

Reaching Beyond Barriers

The 2004 *Reaching Beyond Barriers* conference on May 21st was a great event! The conference was exceptional in every way! Attendance surpassed any of our previous conferences with 266 in attendance. Dr. Gaynell Colburn brought a multidimensional message to kick off the day with her *Ability of You* presentation.

The program was varied and included nationally known speakers,

along with some of our own Arkansas resource folks to share information on cutting edge topics.



Bettie Lou Grinning is the winner of the Quickie wheelchair donated by Sunrise Medical.

The sponsors were generous and brought new elements and technology to the conference, including a premier of the iBot™ power system. The exhibit hall was as popular as any session. And finally, at day's end, we had some super door prizes, including a Quickie manual wheelchair donated by Sunrise Medical. The chair was won by Ms. Bettie Lou Grinning of Hot Springs (who hasn't

ever missed a conference!) and
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The Medicare Drug Program – A Good First Step

Most people who receive Medicare services or have a family member who does are well aware of the controversy last year about legislation to establish a Medicare prescription drug program. There were advocates on both sides, trying to lobby for an affordable program to benefit the millions of Medicare recipients who had no coverage. The drug companies got involved, so did AARP—even the members of the Arkansas congressional delegation were split on the plan.

But eventually, *The Medicare Prescription Drug Improvement and Modernization Act of 2003* was

passed by Congress and signed by the President. Senator Blanche Lincoln, a proponent of the program, described it as “a good first step” to providing adequate prescription benefits to the nation's elderly and disabled citizens. She was likely right. We had to start somewhere, and for now that is a program to be phased in over the next three years.

The Medicare Drug program really has two parts: the discount card, which went into effect on June 1, 2004, and will continue until December 31, 2005, and the actual Medicare program revisions

which will establish prescription coverage under Medicare starting on January 1, 2006. The full details and options of the second phase are not yet available.

Phase One, the Medicare Discount Drug card, may actually benefit ASCC clients who have no other assistance for medication coverage, especially those with lower incomes. If you have any other coverage for prescriptions such as Medicaid or private insurance, you are not eligible for the discount card.

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SPINAL COURIER

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Visit our website at:
www.spinalcord.ar.gov
or e-mail us at:
courier@arspinalcord.org

With Thanks

Donations this quarter from:

**Billy Fryar
Fraternal Order of Eagles,
Jonesboro, AR**

*In Memory of Mr. Zemah Brendle:
Mr. and Mrs. B. E. Brooks*

ASCC accepts tax deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207**

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Voting 101

Dear Editor:

Following the 2000 Presidential Election, the HAVA (*Help America Vote Act*) was enacted. HAVA was designed to make voting easier and more accessible. The Secretary of State's office has published a booklet titled, *Voting 101*. This pocket guide to voting in Arkansas provides information on how to

register, methods of voting, voting misconceptions and a list of all county clerks in Arkansas.

Many of you may feel you cannot vote because you cannot get to the polls. The process for voting absentee is covered in detail in this publication. You may obtain a copy by calling **1-800-247-3312**.

*Kim Brown
ASCC Case Manager
Hot Springs, AR*

From the Director

Lots of good things seem to be happening at the Commission lately. Case Manager Russell Henry tied the knot with fiancée Charlene in June. Our conference was very successful. We got to give away a van and received several unsolicited donations to our program, just at a time when we really need them. Our Commission members are hard at work trying to come up with ways to fund expansions of our services, so that we can truly meet the needs that are out there. Even Medicare seems to be finally coming through with a bit of a drug plan and a promise of review of their 'crack down' on power wheelchair purchases. New projects and programs seem to be cropping up all around us, from regeneration research to return to work initiatives. Things are looking good in spite of ever shrinking budgets.

Unfortunately one person, who was a true advocate for positive change, isn't around to see them. Verlon McKay died on March 22nd. You might not have known Verlon by name, but many of you know of and benefited from his efforts. Verlon McKay lived with his spinal cord injury for over 30 years—it didn't keep him from much. If you use a wheelchair and you vote this fall in an accessible polling place, thank Verlon—he advocated endlessly for accessible polling places before there was a federal law requiring it! If you receive personal care services through In-home Services or Alternatives or Independent Choices, thank Verlon—he was one of the folks who chained themselves to the Governor's desk to prevent cuts in those services. The thing about Verlon is, he didn't really need many of the services he advocated for, but he abhorred inequity and fought hard to prevent it.

I learned a lot from Verlon over the years. I always thought of him as the conscience of our advocacy efforts, always there reminding you that personal choice came first. Verlon McKay was a true advocate. He will be missed.

Cheryl L. Vines

John Holter – Inventor, Philanthropist, Hero

Hero? You don't hear that word used much these days. What did John Holter do that was so heroic?

The year was 1956. John and his wife Mary had tried for ten years to conceive a child and now their newly born son, Casey, had spina bifida and hydrocephalus. The doctors gave little hope for the child, explaining that a shunt could be installed to drain the fluid from around the brain, but the shunt's metal valve would eventually clog, rendering it useless and requiring another surgery.

Desperate to save his son's life, John quizzed the surgeons about shunts and valve design. Although John had never been to college, he was a skilled mechanic employed at a local door lock manufacturing company. Working frantically in a garage shop behind his home, John designed, tested and discarded numerous metal valves. He was only successful when he switched

to a new material developed during WWII—silicone.

His simple valve design allowed fluid to flow one way, away from the brain, and didn't clog up. Within weeks of Casey's birth, a shunt with John's newly designed silicone valve was implanted by surgeons and saved the life of his son.

John Holter's revolutionary shunt valve was quickly accepted by the medical community and saved the lives of hundreds of thousands of newborn children and others with hydrocephalus. He took the shunt valve to medical meetings outside the country, giving them free to those in need.

As a result of John's shunt valve, mortality from hydrocephalus surgery went from 70 percent in the early 1950s to 33 percent in the late 1950s, to around 10 percent in the 1970s. Today the mortality rate is less than one percent.

John went on to create other medical devices, such as: dialysis pumps, artificial heart valves, finger tendons and other inventions. But, he is best known for the silicone shunt valve.

Throughout his life he supported research into hydrocephalus and spina bifida and was a tireless advocate for improving the lives of those with spina bifida. In 1976, the University of Sheffield in England awarded him an honorary doctorate for the development of the shunt valve. Many in the medical community thought he should have been awarded the Nobel Prize. In later life he gave away large sums of money to local charities, saying he wanted to see the money do some good while he was still alive.

John Holter died December 22, 2003, in Devon, PA. He was 87 years old.

FOE Donation to ASCC

The Fraternal Order of Eagles (FOE) Jonesboro Chapter made a donation of \$2,000 to ASCC in April. The donation was funded in part by the FOE *Lewis Reed Spinal Cord Injury Fund*.

This donation will be used to support several

Commission projects including the Education and Resource Center, patient education resources and summer camp for children with spinal cord disabilities. Fraternal Order of Eagles Worthy President Doug Mathis (*pictured above, center*) of Jonesboro presented the check to Commission Chairman Jimmy Ashley (*right*) and Executive Director Cheryl Vines (*left*).



Governor's Scholarship Recipients Announced

Fifteen Arkansans with disabilities received \$1,200 scholarships from the Governor's Commission on People with Disabilities at an awards banquet on May 13, 2004. Recipients included four ASCC clients:

- Tyler Garner (Hot Springs) is a graduate from Lake Hamilton High School and plans on majoring in Journalism at the University of Texas, Arlington.
- Bryce Humbrecht (Batesville), currently attending the University of Arkansas Community College at Batesville, is working on a degree in web design.
- Mary Allison Milford (Magnolia), graduated from Magnolia High School and plans to pursue double majors in History and Political Science at the University of Alabama.
- Heidi Wofinbarger (Green Forest) graduated from Berryville High School and will be attending North Arkansas College. She plans to transfer to the University of the Ozarks to major in graphic design.

Congratulations to all the recipients of the Governor's scholarships!

Common Medications Used in SCI Medicine

Part Three – Pain

By Tom Kiser, M.D., ASCC Medical Director

Pain is very common in spinal cord injury (SCI) and can be due to multiple factors. It can be classified as it relates to the level of the neurological injury: above-level, below-level and at-level pain; and whether the pain is due to central nervous tissue damage (neuropathic) or to body tissue damage (nociceptive). To be effective, the treatment has to be directed at the cause of your pain.

Above-level pain is in the area of normal nerve function. A common problem is muscle and joint pain in the region of the neck, back or shoulder. This may be due to poor posture, muscle or tendon injury or joint arthritis. Nerve entrapment of the peripheral nerves, as occurs in carpal tunnel syndrome, can also cause pain. There are a multitude of medications which can be used to treat these aches and pain, but a general principle is that *the focus should be on preventing further problems and improving function.*

You want to use the *medication with the most benefit and the least side effects.* For general muscle aches and arthritis, **nonsteroidal anti-inflammatory drugs** (NSAIDs) such as ibuprofen (Motrin) or naproxen (Aleve) can be used to decrease inflammation and swelling temporarily, but are sometimes also used long-term to control arthritic pain.

A new class of medications called **Cox-2 inhibitors**, including celecoxib (Celebrex), rofecoxib

(Vioxx) or valdecoxib (Bextra), are more selective and decrease some of the side effects. The main side effect to watch out for is stomach irritation with possible gastrointestinal (gut) bleeding. If it is used long-term for pain control, then blood work has to be checked periodically to monitor blood count, kidney and liver function. If you have asthma it can cause it to become slightly worse. Narcotics should be used very carefully for above-level pain, remembering the problems of constipation, tolerance to the drugs and the potential for addiction.

Below-level pain is a hard-to-describe pain that is due to spinal cord damage. This is often called central pain, because it is a result of damage to the central nervous system nerves, which process

the information about pain. Due to the damage, any input to the nerves is misinterpreted and is often perceived as pain by the individual. **Anti-seizure medications** such as carbamazepine (Tegretol), gabapentin (Neurontin), and levetiracetam (Keppra) can help change the nerve conduction and help decrease the pain.

Carbamazepine can be used in a dosage of 200-400 mg. two times a day. It can cause drowsiness, and blood work is required to ensure you do not develop anemia or liver problems. Gabapentin has also been quite useful. Its side effects are minimal, and it does not require routine blood work. The Gabapen-

tin daily dosage is 100-3600 mg. in divided doses. Some medications

known as

tricyclic antidepressants, such as amitriptyline (Elavil) or nortriptyline (Pamelor), can also be used to decrease pain and help with improving sleep at night.

Narcotics such as Morphine, Oxycodone and Hydrocodone are the last class that should be used to manage central pain. They are full of potential problems and pitfalls and *should only be used as a last resort.* The goal of narcotics is to improve the ability of the individual to function, not to eliminate the pain. The patient and the physician must have a written understanding and use the smallest dose which will control the pain.

At-level pain is usually due to damage to the nerve root at the level of the spinal cord injury or an abnormal interpretation of the nerve signal by the spinal cord at that level. Patients often describe it as a band-like sensation around their chest wall. Normal touch may not be interpreted correctly, making the individual perceive a feeling of pain.

This can be treated with medications which alter nerve function, such as anti-seizure medications, tricyclic antidepressants, and sometimes a **topical medication** which desensitizes the nerve, such as an arthritis cream or a cream with Capsaicin in it. Capsaicin comes from the Capsaicin chili pepper and may reduce substance P, a pain neurotransmitter within the nerve.

Often the side effects of the treatment for pain are worse than the

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Tom Kiser, M.D.

Better positioning in the wheelchair, strengthening and stretching with physical therapy, and using minimal medications are often the best methods of treatment.

White County Support Group Enjoys a Picnic Perfect Day

The White County Support Group Picnic was held at Riverside Park in Searcy Friday, June 4th, from 11:00 a.m. to 3:00 p.m. Terra Patrom of Quantum Rehab provided the tasty main dish of pulled-pork barbecue and buns



Larry Wilson of Bald Knob is having a great time visiting with friends at the White County Support Group picnic.



Kathy Stuart and Mike Wagner of Heber Springs enjoy the delicious barbecue.

and MidSouth Medical and Mobility provided the paper plates, plastic ware and cups. Support group members also brought side dishes to complement the barbecue, including: baked beans, beans and sausage, potato salad, chips, a vegetable plate and a variety of cheesecakes for dessert (yum!).

Approximately 30 people attended this annual event and a great time was had by all! It was perfect picnic weather, allowing the children ample time on the playground,

and the adults opportunity to socialize, while leisurely grazing around the food table. Of course, upon leaving the park everyone's stomach was full and all faces were smiling!



Elvin and Carol Whitehead of Carlisle are enjoying the picnic.

Please contact ASCC if you are interested in learning more about our monthly support groups. We thank all who participated in making the White County Picnic 2004 a success, and welcome any suggestions or ideas you may have for our picnic in 2005!

Pain Treatment

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pain itself. You want to address any reversible aspects of pain with treatment. Better positioning in the wheelchair, strengthening and stretching with physical therapy, and using minimal medications are often the best methods of treatment.

Surgery can be a highly successful option with nerve entrapments such as carpal tunnel syndrome, but is usually combined with therapy and medication. For at-level and below-level pain, surgery can be helpful in diminishing the pain but involves the cutting of nerves and/or small areas of the spinal cord to decrease the nerve input. *This is a treatment of last resort.*

In the next issue of the newsletter I will discuss bowel medications commonly used in spinal cord injury.

Teddy Hart – Recipient of Donated Van

David Hare, son of ASCC client Alanette Hare of Little Rock, donated a fully accessible, gently used Dodge van to the Commission to be given to a needy client. The Commission solicited applications and over 46 were received. Since all of the applicants had great need, one application was drawn randomly to receive the van.



The lucky recipient was Teddy Hart of Jonesboro, AR. Pictured above (*second from left*), he accepts the keys from ASCC Commission Chairman Jimmy Ashley (*far left*), Executive Director Cheryl Vines (*second from right*) and Jonesboro Case Manager Russell Henry (*far right*).

Up Close and Personal: Kay Lynn

This is the third in a series of articles profiling the ASCC Case Managers.



Kay Lynn obtained her B.A. degree from Arkansas Tech University in Russellville and has attended UALR for several summers in the past working on her Masters in Counseling. Over the years she has developed her skills in crisis case management, family counseling and needs assessment in numerous areas of the health care system.

In 1989 Kay brought her skills and experience to the Arkansas Spinal Cord Commission (ASCC). As a Licensed Social Worker, Kay utilizes her facilitating techniques, advocating strongly for the individuals with spinal cord injuries in Northwest Arkansas. A lifelong resident of Crawford County, Kay utilizes her knowledge of the area in locating “that hard to find” resource or service. According to Client Services Administrator Patti Rogers, “If there is a resource to be found in Northwest Arkansas, Kay knows about it.”

Over the past few years Kay has been very instrumental in coordinating a Wheelchair Clinic in the Fort Smith area to assist her clients who are in need of an evaluation. Kay has also developed positive working relationships with the staff at the local acute care and rehabilitation hospitals, ensuring that anyone with a spinal cord disability does not go unnoticed or without the much-needed services.

In addition to her expertise in Case Management, Kay has always had a passion for writing. She has a quick wit with journalistic flair and over the past few years has a series of articles printed in the Fort Smith newspaper. Kay continues to write short stories in her “spare time,” so don’t be surprised if she appears on the cover of a best seller one day soon!

PROFILE:

Date And Place Of Birth: August 18, 1941, in Fort Smith, AR

The Animal I Most Identify With Is: Jaguar or . . . Mercedes!

I Absolutely Will Not Eat: Are you KIDDING? If it’s edible, I’ll eat it!

If I Did Not Live In Van Buren, I Would Want To Be: On the French Riviera

My Favorite Movie Is: *Gone With the Wind*

My Favorite Song Is: *Born to Be With You* (an oldie! by the Chordettes)

The Guests At My Fantasy Dinner Party Would Be: Marlon Brando, Harvey Keitel, Willem Dafoe and Truman Capote

I Am Most Comfortable With People Who Have: A good sense of humor

My Favorite Pastime Is: Reading for pleasure

My Pet Peeve Is: Human service providers who try to see what they CANNOT provide rather than what they can

The Best Advice I Ever Received Was: Carpe diem (seize the day)

My Favorite Saying Is: Don’t sweat the small stuff

I Knew I Was Grown Up When: As a discharge planner at age 40 in the local Humana-run hospital, I heard my sixth grade teacher (my Miss Dove), who was trying to plan for her sister after a massive stroke, say, “I just don’t know what to do. Can you help me?”

The Latest Book I’ve Read Is: Willa Cather’s *Professor’s House*

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Be a published author

My New Hobby Is: Nothing new here

One Word To Sum Me Up: Impassive-Aggressive

The New Medicare Drug Program

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Medicare Discount Drug Program

The Discount Drug cards are available through private companies, at a small annual fee, and will allow participants to receive a discount of 10 to 30% on each prescription. The Discount Drug cards cost up to \$30, but the savings over the course of the year could significantly exceed the cost. For example, if you have a prescription that costs \$50 each month, you may save \$5 to \$18 on the cost, depending on the discount. That is an annual savings of \$30 to \$186 above the cost of the card.

The Low Income Credit

If you are a Medicare recipient and your monthly income is \$1,047 single or \$1,405 married, you may be eligible for a \$600 annual credit on the Medicare Drug Discount card that you choose. This is an annual credit, with \$600 available for 2004 and \$600 available for 2005. You would be able to apply the discount on 90% of each drug purchase, until you have used your \$600 credit. For example, if you have a medication that costs \$50, you will pay \$5 and \$45 will be deducted from your credit; you will "spend down" your credit until it is gone. This will be especially helpful to folks who have an illness or infection and need an expensive course of medicines at one time. If you are eligible for the low income credit, your Discount Drug card is free, but you must sign up for one of the cards in order to access the credit.

Choosing a Card

You must be careful in selecting your Medicare Discount Drug card, as different cards have discounts for different drug companies. Depending on the maker of the drugs you take most frequently, you should choose the card that provides maximum coverage. If you are in a Medicare managed care program, contact them about your card. You may also want to talk with your pharmacist to determine your best options.

Applying for a Card

Medicare is a great source of information about the Discount Drug Card program. You can go to their website at www.medicare.gov and select "Prescription Drug and Other Assistance Programs." There is a questionnaire that will help you select the best plan for your needs. If you do not have access to the Internet, you can call Medicare at **1-800-MEDICARE** (1-800-633-4227) and a worker will help you with the information. When you call, be sure that you have a list of all of your medications in front of you, as you will need those to determine your best plan. There are about 30 Medicare approved discount cards. Once you determine the best plan for you, contact the provider company to apply for a card on their web site by phone or by mail. You will receive a Discount Drug card in the mail. A survey of four Pulaski county pharmacies (national grocery chain, national drug store chains and locally owned pharmacy) reflected that those pharmacies accepted all of the Medicare approved Discount Drug cards. You may want to check with your own local pharmacy to be sure they accept the cards.

As with any federal program, there is no "simple" way to access the card. It may take you an hour or more on the computer or on the phone to determine the best card and apply for it. However, you only have to do it once, and you will have services through the end of 2005. So, *the sooner you apply, the sooner you will see the savings!* If you need help applying, a family member or friend can apply for you, as long as they have the needed information.

User Beware

Only Medicare approved Discount Drug Cards are eligible for discounts and the low income credit. Be sure that the card you buy is Medicare approved. Attorney General Mike Beebe informs us that there are already a lot of scams related to this program. Do not pur-

50+ With Spina Bifida?

If you have spina bifida and are age 50 or older, chances are you are a member of an elite group. Nancy Bauman hopes to write a book about your generation. Please contact Nancy Bauman, 703 Chestnut Street, Mantorville, MN 55955, or e-mail nbauman@kmtel.com.



SAILS PlayDay

Come enjoy the water and fun activities! The Spa Area Independent Living Services (SAILS) will be hosting its annual PlayDay at Lake DeGray near Arkadelphia, AR on Saturday, **August 28, 2004**.

For more information, call Brenda Stinebuck at **501-624-7710** or toll-free **800-255-7549**.

chase discount cards from a door-to-door salesperson, by telephone solicitation or a mailed offer, without checking it out with Medicare first. Your local pharmacy may be selling discount cards. If so, make sure it is Medicare approved. And remember, if you have Medicaid coverage, there is no use for you to purchase a discount card, as you will not be eligible to use it. Good information booklets on the Medicare Discount Drug programs are available through Medicare, AARP and other agencies serving folks who are elderly or with disabilities. *Be an informed consumer.*

A Good First Step

The Medicare Prescription Discount Drug card is a good first step. Medicare recipients with monthly drug bills of \$100 to \$200 will see a savings of \$20 to \$60 per month. For many low income Medicare recipients, the \$600 credit will be a big help. The second phase of prescription coverage will go into effect in January 2006. Additional information on that aspect of the program will be available as that time nears.

2004 Conference

Continued from page 1

since she doesn't use a chair, she gave it to Ronnie Brown of North Little Rock, who will put it to good use!

Conferences don't just happen; they are the result of a lot of hard work. Thanks and kudos go to the Commission's Little Rock staff who coordinated the event, our speakers, sponsors, exhibitors and volunteers, as well as those of you who attended because as one person remarked, "I learn as much talking to other people at the conference as I do in the sessions."



Keynote Speaker Gaynell Colburn, M.D., Ph.D. of Baltimore addresses the topic, "The Ability of You."



Barbara Blockburger is the happy winner of a \$20 gift card.

Please go to the Arkansas Spinal Cord Commission (ASCC) website www.spinalcord.ar.gov to see more photographs from the 2004 *Reaching Beyond Barriers* conference.

Upcoming ADSA Activities

The Arkansas Disabled Sportsman Association (ADSA) will be hosting fun and exciting outdoor activities this summer. For information on how you and your family can participate, contact Tony LeQuieu at **870-933-5254** or Jimmy Ashley at **870-935-6875**.

- July 24 Gun Shoot for black powder and .22 caliber. Contact Tom Cannon at **501-843- 2028**
- Aug. 20-22 Camping at Heber Springs in JFK Park. Contact Tony LeQuieu at **870-933-5254**
- TBA ATV Ride and Fish Fry at Cherokee Park. Contact Tony LeQuieu at **870-933-5254**

Also, there will be Sports Shows at El Dorado (**September 10-11**), Memphis (**August 13-15**) and Little Rock (**August 27-29**). For more information about these sports shows, please contact Jimmy Ashley at **870-935-6875**.

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